AN ANALYSIS OF THE "ANGELINA JOLIE EFFECT": DOES THE MEDIA INFLUENCE PATIENTS' CONTRALATERAL PROPHYLACTIC MASTECTOMY DECISIONS?

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Abstract

Research Question: Do printed articles about prophylactic mastectomy appearing in popular magazines increase the number of women who elect to undergo contralateral prophylactic mastectomy (CPM)? This study is a retrospective review that examines the temporal relationship between articles written about prophylactic mastectomy that have appeared in popular magazines and the number of CPM performed.

Background: Following genetic testing and counseling, many women elect to undergo prophylactic surgery to reduce their risk of developing breast and ovarian cancer. Bilateral prophylactic mastectomy (BPM) can decrease a woman's risk of developing breast cancer by more than 90%.[4] However, CPM does not increase survival for the majority of women with breast cancer, which is contrary to the increasing incidence of CPM.[5,7] Angelina Jolie published an op-ed in *The New York Times* in May 2013 regarding her decision to undergo BPM. She pursued preventative surgery due to her strong family history of breast cancer and positive test for a BRCA mutation. While Jolie's situation is not analogous to that of women undergoing CPM, it is possible that in many women's minds, the situations are similar.

Methods: The National Cancer Institute SEER database was utilized to obtain data regarding the number of CPM surgeries performed from 2004 to 2015. Four rate sessions were run that included site specific surgery codes associated with women age 20 to 79 of all races who were diagnosed with breast cancer between 2004 and 2015. Academic OneFile and Academic Search Ultimate databases were accessed using the keyword "mastectomy" and the publication title for each magazine to search for articles from 2004 to 2015 that met inclusion and exclusion criteria. Data analysis was performed utilizing the chi-squared test, Fisher's exact test of trend, and Spearman's correlation. All p-values were two-sided and $p < 0.05$ was considered statistically significant. All data analysis was conducted using STATA Version 14 (College Station, TX).

Results: 223,316 women from ages 20 to 79 of all races were diagnosed with breast cancer and assigned breast site specific surgery codes (C50.0-C50.9) from 2004 to 2015 in the SEER database. Of these women, 22,405 (10.03%) were assigned site specific surgery codes for CPM. There were 44 magazine articles that met the inclusion and exclusion criteria.

Conclusions: There is a statistically significant increasing trend in the number of CPM surgeries performed ($p < 0.001$). Likewise, there is a statistically significant increasing trend in the number of magazine articles published ($p < 0.001$). However, Spearman's correlation demonstrates a 56% correlation ($\rho = 0.56$) with a p-value of $p = 0.059$, which is almost but not quite statistically significant. This suggests that there is possibly a correlation between the number of magazine articles published and the number of CPM surgeries performed, but it does not prove that they are correlated. Therefore, our hypothesis cannot be confirmed with certainty.

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Introduction/Significance

Breast Cancer and BRCA1 and BRCA2

Approximately 5-10% of all female breast cancer is hereditary, with the majority of heredity breast cancers caused by mutations in two breast cancer genes called BRCA1 and BRCA2.[4] Women who are positive for the BRCA1 and BRCA2 mutations have a significantly increased risk of developing breast cancer by age 70. The risk for BRCA1 carriers is 57%, and the risk for BRCA2 carriers is 49%.[4] In comparison, the average lifetime risk of developing breast cancer is 12% for women who do not carry these two gene mutations.[4]

Background of Prophylactic Mastectomy

Following genetic testing and genetic counseling, many women elect to undergo prophylactic surgery to reduce their risk of developing breast cancer and ovarian cancer. There are two components of prophylactic surgery: mastectomy, the removal of the breasts, and oophorectomy, the removal of the ovaries. Bilateral prophylactic mastectomy can decrease a woman's risk of developing breast cancer by more than 90%.[4] In addition, prophylactic oophorectomy decreases a woman's chances of developing ovarian cancer by 80%[4]; this also reduces the risk of developing breast cancer by 50%.[4] There are several indications for women to consider bilateral prophylactic mastectomy, including BRCA1 or BRCA2 mutations or other genetic mutations associated with breast cancer risk, strong family history with no pertinent genetic mutations, histological risk factors, and difficult surveillance.[8]

Unlike bilateral prophylactic mastectomy for women who are considered high risk, contralateral prophylactic mastectomy (CPM) does not increase survival for the majority of women with unilateral breast cancer who do not belong to this high risk category.[7] However, there has been a 300% increase in CPM from 1997 to 2005.[5] In addition, the risk of contralateral breast cancer in most women is relatively low. In a study of 134,501 patients from 1973 to 1996, only 4.2% of patients were diagnosed with contralateral breast cancer.[3] In light of this evidence, it is unclear why such a large number of women are still electing to undergo CPM in spite of the lack of significantly increased survival rates. It is possible that women with

unilateral breast cancer in the average risk category incorrectly assume that the benefit derived from BPM in high risk women also applies to their decision to undergo CPM due to a misinterpretation of the data.

Despite data demonstrating that bilateral prophylactic mastectomy significantly reduces a woman's risk of developing breast cancer, it also may result in potential surgical complications, permanent changes in physical appearance, and potential changes in health-related quality of life.[8] Consequently, the decision to undergo prophylactic mastectomy should be carefully discussed between a patient and her physician, often after the completion of genetic counseling. When utilizing shared decision making with patients to decide whether or not to pursue prophylactic surgery, it is important to "be mindful of risks of aggressive surgery while taking into account patients' desires".[1]

The "Angelina Jolie Effect"

Angelina Jolie, a popular American actress and humanitarian, published an op-ed in *The New York Times* in May 2013 regarding her decision to undergo bilateral prophylactic mastectomy. Jolie made the decision to pursue preventative surgery due to her strong family history of breast cancer and positive test for a BRCA mutation. Since her announcement, the demand for BRCA testing in women who are at high risk for BRCA mutations has more than doubled.[4] This phenomenon has been dubbed the "Angelina Jolie effect." Jolie's decision to publicize her medical journey has "helped normalize both prophylactic surgery and the concept of genetic testing and counseling," according to Mercy Laurino, a genetic counselor at Seattle Cancer Care Alliance.[6] Many oncologists and genetic counselors agree that her announcement has helped to reduce the stigma associated with mastectomy and to promote awareness and increase dialogue about hereditary risks of breast cancer.[6]

Research Question/Hypothesis

Do printed articles about prophylactic mastectomy appearing in popular magazines increase the number of women who elect to undergo contralateral prophylactic mastectomy (CPM)? We hypothesize that more women elect to undergo CPM as greater attention in popular magazines is given to these prophylactic mastectomy procedures. If more contralateral prophylactic mastectomies are performed as greater popular magazine attention is focused on the procedure, then it is likely that this type of media has a significant effect on the behavior of individuals with respect to a preventative surgery like CPM.

Rationale/Goals for Study

Although there has been a consensus that the "Angelina Jolie effect" has increased awareness of the hereditary risks of breast cancer and prophylactic mastectomy as a preventative measure, it is unclear to what extent her announcement has influenced the number of women with unilateral breast cancer who elect to undergo contralateral prophylactic mastectomy. There have been relatively few studies done regarding the relationship between her announcement and the incidence of prophylactic mastectomies. Studies that have been completed have primarily been focused on narrow populations (for example, only at a single hospital) or have not attempted to correlate the incidence of prophylactic mastectomies with media attention to Jolie's announcement. One such example is a study by Evans et al. in *Breast Cancer Research*, which only examined the number of bilateral risk-reducing mastectomies "carried out at Wythenshawe and Christie hospitals per 6-month period from 2011 and proportion with mutations in high-risk genes".[2] This project will help determine the relationship between popular magazine attention and the number of contralateral prophylactic mastectomies performed on a yearly basis. In addition, we hope to apply the "Angelina Jolie effect" to a broader context in order to examine the relationship between media coverage and patient decision making.

Materials and Methods

National Cancer Institute Surveillance, Epidemiology, and End Results (SEER) Database Surgical Data

Data was collected from National Cancer Institute SEER database regarding the number of contralateral prophylactic mastectomy surgeries performed between January 1, 2004 and December 31, 2015. The first rate session that was run included all of the following site specific surgery codes (C50.0-C50.9, C50.42, C50.47, C50.48, C50.49, C50.52, C50.57, C50.58, C50.59, C50.62, C50.63, C50.68, C50.69, C50.72, C50.73, C50.74, C50.75, All [defined as the previously mentioned codes except for C50.0-C50.9]) associated with women age 20 to 79 of all races who were diagnosed with breast cancer between 2004 and 2015. The output for the first rate session utilized summary stages (In Situ; Local; Regional, Direction Extension [RE]; Regional, Lymph Node Only [RN]; RE + RN; Regional, Not Otherwise Specified; Distant, Not Applicable; Unknown/Unstaged) as the columns and site specific surgery codes as the rows.

The second rate session that was run included the same population as the first rate session, but with an output that utilized age in years (20-24, 25-29, 30-34, 35-39, 40-44, 45-49, 50-54, 55-59, 60-64, 65-69, 70-74, 75-79) as the columns and site specific surgery codes as the rows.

The third rate session that was run included the same population as the first rate session, but with an output that utilized race (All Races, White, Black, Other, Unknown) as the columns and site specific surgery codes as the rows.

The fourth rate session that was run included the same population as the first rate session, but with an output that utilized year of diagnosis (2004, 2005, 2006, 2007, 2008, 2009, 2010, 2011, 2012, 2013, 2014, 2015) as the columns and site specific surgery codes as the rows.

All outputs for the four rate sessions were manually entered into Microsoft Excel using the same layout for columns and rows in order to allow for data analysis.

Popular Magazine Data

Through the University of Arizona Health Sciences Library website, the Academic OneFile database and Academic Search Ultimate database were accessed. The keyword "mastectomy" and the publication title for each magazine (for example, "*Women's Health*") were used to search each database for articles. The search results were narrowed by year to include 2004-2015. The magazines used included *People Magazine*, *Cosmopolitan*, *TIME*, *Newsweek*, *O, The Oprah Magazine*, *Prevention*, *Women's Health*, *Health*, and *Shape*. Each article was manually read to determine if it met inclusion and exclusion criteria. Images, paid advertisements, articles less than 100 words long, and articles that only briefly mentioned prophylactic mastectomy were excluded. Article title, publishing date, author, database, and keyword path were recorded in Microsoft Excel for each article. The total number of articles per year were summed and recorded in Microsoft Excel.

Statistical Analysis

Patient (age, race, and year of diagnosis) and data characteristics (summary stages) were reported as frequencies and percentages. The chi-squared test/Fisher's exact test of trend was used to ascertain relationships between the percentage of surgeries relative to age, race, and year of diagnosis, respectively. Spearman's correlation was used to correlate the number of magazine articles related to prophylactic mastectomies and the number of contralateral prophylactic mastectomy surgeries over time. All p-values were two-sided and $p < 0.05$ was considered statistically significant. All data analysis was conducted using STATA Version 14 (College Station, TX).

Statistical analysis for all data was performed following the advice of Paul Kang, biostatistician.

At-Risk Aspects

There are no identified risks associated with this study. All information is publicly accessible and therefore does not contain any patient-identifiable information.

Results

A total of 223,316 women from ages 20 to 79 of all races were diagnosed with breast cancer and were assigned breast site specific surgery codes (C50.0-C50.9) from 2004 to 2015 in the National Cancer Institute's SEER database. Of these women, 22,405 (10.03%) of them were assigned site specific surgery codes that indicated they underwent contralateral prophylactic mastectomy (CPM) surgeries. These site specific surgery codes include the following: C50.42, C50.47, C50.48, C50.49, C50.52, C50.57, C50.58, C50.59, C50.62, C50.63, C50.68, C50.69, C50.72, C50.73, C50.74, and C50.75.

The majority of women who underwent CPM surgeries were diagnosed with breast cancer that was characterized with the summary stage "Local" (n = 12,812, 57.18%), which is defined as confined to the organ of origin (Table 1). The age group with the most women who underwent CPM surgeries was age 45-49 years old (n = 3814) (Table 1). However, the age group with the most women diagnosed with any breast cancer site specific surgery code (n = 33,172) was 60-64 years old (Table 1). The race with the most women who were assigned any breast cancer site specific surgery code (n = 174,667) and also the most women who underwent CPM surgeries (n = 18,918) was White (Table 1). The year of diagnosis with the most women who were associated with any breast cancer site specific surgery code (n = 21,072) was 2015, whereas the year of diagnosis with the most women who underwent CPM surgeries (n = 2669) was 2013 (Table 1).

There were 44 magazine articles about prophylactic mastectomy that met the inclusion and exclusion criteria published from 2004 to 2015. The year with the most magazine articles published (n = 14) was 2013 (Table 2). This same year was also the year with the most women who underwent CPM surgeries (n = 2669) (Table 2). Spearman's correlation demonstrates that $\rho = 0.56$ with a p-value of $p = 0.059$ (Figure 1).

Table 1. *Characteristics of Women Assigned Breast Site Specific Surgery Codes and Women Assigned Contralateral Prophylactic Mastectomy Site Specific Surgery Codes*

Variable	Total* (n = 223,316)	All** (n = 22,405)	%***	p-value
Summary Stage				
In Situ	0	0	0	
Local	143,039	12,812	5.94	
Regional, Direct Extension Only	3462	301	0.14	
Regional, Lymph Nodes Only	54,859	7659	3.55	
Regional, Direct Extension + Nodes	7588	1064	0.49	
Distant	11,857	530	0.25	
Unknown/Unstaged	2511	39	0.02	
Age in Years				p < 0.001
20-24	204	61	0.03	
25-29	1104	306	0.14	
30-34	3339	940	0.42	
35-39	7644	1948	0.87	
40-44	15,943	3124	1.40	
45-49	24,221	3814	1.71	
50-54	29,666	3504	1.57	
55-59	31,298	2937	1.32	
60-64	33,172	2513	1.13	
65-69	30,462	1763	0.79	
70-74	24,521	982	0.44	
75-79	20,742	513	0.23	
Race				p < 0.001
All Races	223,316	22,405	10.03	
White	174,667	18,918	8.47	
Black	24,561	1910	0.86	
Other (American Indian/Alaska Native, Asian/Pacific Islander)	22,853	1491	0.67	
Unknown	1235	86	0.04	

Year of Diagnosis				p < 0.001
2004	16,608	775	0.35	
2005	16,640	851	0.38	
2006	16,932	1141	0.51	
2007	17,486	1445	0.65	
2008	17,914	1714	0.77	
2009	18,545	2000	0.90	
2010	18,395	2106	0.94	
2011	19,254	2280	1.02	
2012	19,573	2459	1.10	
2013	20,146	2669	1.20	
2014	20,751	2520	1.13	
2015	21,072	2445	1.09	

*Defined as all women assigned site specific surgery codes for breast cancer (C50.0-C50.9).
**Defined as all women assigned site specific surgery codes for contralateral prophylactic mastectomy (C50.42, C50.47, C50.48, C50.49, C50.52, C50.57, C50.58, C50.59, C50.62, C50.63, C50.68, C50.69, C50.72, C50.73, C50.74, C50.75).
***Defined as the percentage of patients assigned site specific surgery codes for contralateral prophylactic mastectomy ("All") out of the total number of patients assigned site specific surgery codes for breast cancer (n = 223,316).

Table 2. *Number of Magazine Articles and CPM Surgeries Per Year*

Year	Magazine Articles Published (n = 44)*	CPM Surgeries (All) Performed (n = 22,405)**
2004	2	775
2005	0	851
2006	1	1141
2007	7	1445
2008	2	1714
2009	1	2000
2010	3	2106
2011	7	2280
2012	2	2459
2013	14	2669
2014	3	2520
2015	2	2445

*$p < 0.001$ for Magazine Articles Published using Fisher's exact test.
**$p < 0.001$ for CPM Surgeries (All) Performed using chi-squared test.

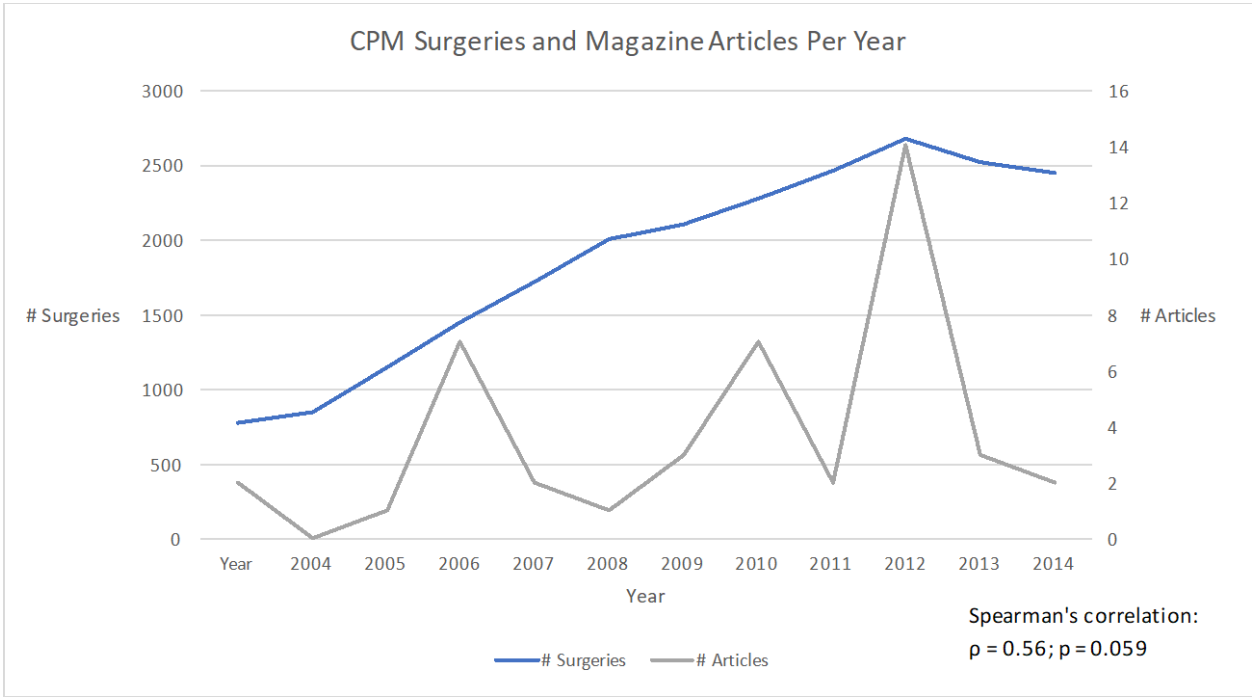

Figure 1. *Number of CPM Surgeries and Magazine Articles Per Year*

Discussion

Although many scientific journal articles discuss the representation of plastic surgery in popular magazines, comparatively few assess the relationship between the incidence of a plastic surgery procedure and its prevalence in popular magazine articles. This project aimed to determine the nature of this relationship for contralateral prophylactic mastectomy.

There has been a consensus that the "Angelina Jolie effect" has increased awareness of the hereditary risks of breast cancer and prophylactic mastectomy as a preventative measure; however, it is unclear to what extent the media coverage of her announcement has influenced the number of women who elect to undergo a contralateral prophylactic mastectomy. Relatively few studies have been done regarding the relationship between her announcement and the incidence of contralateral prophylactic mastectomies. This project sought to determine the relationship between popular magazine attention and the number of contralateral prophylactic mastectomies performed on a yearly basis at a national level.

We hypothesized that if more contralateral prophylactic mastectomies were performed as greater popular magazine attention was focused on the procedure, then it is likely that this type of media has a significant effect on the behavior of individuals with respect to a preventative surgery such as contralateral prophylactic mastectomy.

Data analysis using the chi-squared test demonstrates that the distribution of site specific surgery codes among white women is different than among other races ($p < 0.001$) (Table 1). There is a statistically significant relationship in the percentage of site specific surgery codes between races (Table 1). Similarly, there is a statistically significant relationship in the percentage of site specific surgery codes between age groups ($p < 0.001$) (Table 1).

The overall trend of the number of CPM surgeries performed is increasing, as demonstrated by the blue line in Figure 1. Using the chi-squared test, there is a statistically significant increasing trend in the number of CPM surgeries performed ($p < 0.001$) (Table 2). The gray line in Figure 1 appears to demonstrate an overall increase in the number of magazine articles published on this subject over time. Using Fisher's exact test, there is a statistically

significant increasing trend in the number of magazine articles published ($p < 0.001$) (Table 2). However, Spearman's correlation demonstrates a 56% correlation ($\rho = 0.56$) with a p-value of $p = 0.059$, which is almost but not quite statistically significant. This suggests the possibility of a correlation between the number of magazine articles published and the number of CPM surgeries performed, but it does not prove that they are correlated. Therefore, our hypothesis that more women elect to undergo CPM as greater attention in popular magazines is given to these prophylactic mastectomy procedures cannot be confirmed with certainty.

Although we were not able to confirm our hypothesis with a statistically significant correlation between the increasing trends in the number of magazine articles published and the number of CPM surgeries performed, the p-value ($p = 0.059$) of Spearman's correlation was extremely close to the threshold for statistical significance ($p < 0.05$). This suggests that it is possible that there is a relationship, but further studies are required to ascertain whether both of the increasing trends are correlated with each other.

Future Directions

As mentioned previously, further studies are required to ascertain whether or not the increasing trends in the number of magazine articles published and the number of CPM surgeries performed are significantly correlated with each other. This study opens the door for future research into the significance of media forms such as popular magazines with respect to patients' decisions about elective surgeries. Understanding the factors that influence patients' decisions regarding their health is paramount to delivering quality care.

This focus of this project was solely on popular magazine articles; however, print readership has steadily declined since the advent of various forms of digital media, like television, social media, and blogs. Nor did this project include other categories of printed media, such as newspapers and journals. It is possible that other types of print or digital media have a stronger influence on patient decision making than popular magazine articles do. Future studies could address this weakness in our study by including other forms of print and digital media in their analysis.

Furthermore, this project only included print media that is published in English, which could limit the population examined given that many Americans speak and read a language other than English. Similarly, socioeconomic limitations could exist due to the possibility that less educated individuals were less likely to read the popular magazine articles included and that less wealthy individuals were less likely to purchase the magazines in order to read the articles. Future studies could include media in other languages and from other sources in order to expand the population examined in this project.

Conclusions

In summary, we were not able to confirm our hypothesis that there is a statistically significant correlation between the increasing trends in the number of magazine articles published and the number of CPM surgeries performed. However, the p-value ($p = 0.059$) of Spearman's correlation was extremely close to the threshold for statistical significance ($p < 0.05$). This suggests that it is possible that there is a relationship, but future research is required to ascertain whether both of the increasing trends are correlated with each other.

If further studies are able to prove a significant correlation, then it is possible that popular magazines could be harnessed as a means of disseminating important information regarding health, like the use of prophylactic mastectomy as a preventative measure against breast cancer. Public health entities could utilize popular magazines, like *Cosmopolitan*, in order to raise awareness about important issues related to health and wellness. In addition, plastic surgeons could distribute information through popular magazines to educate individuals regarding surgical procedures, safety, risks, and benefits.

If further studies confirm that there is no significant relationship between the number of popular magazine articles and the number of prophylactic mastectomies performed, then it is likely that those magazines do not have a significant impact on the behavior of individuals with respect to the decision to undergo prophylactic mastectomy. In this case, it is possible that other factors or forms of media are responsible for influencing patients' decisions.

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